



LONG-TERM CARE AND DISABILITY RESEARCH

1989-1992

Sponsored by
The Division of Long-Term Care
and Aging Policy

LONG-TERM CARE AND DISABILITY RESEARCH

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INTRODUCTION

This booklet of Long-Term Care and Disability Research has been prepared by the Division of Long-Term Care and Aging Policy, Office of Family, Community and Long-Term Care Policy (FCLCP), Office of the Assistant Secretary for Planning and Evaluation (ASPE). It summarizes the results of the Division's research projects from 1989 through the present and highlights future plans. A previous edition of the booklet summarized the Division's research from 1985 through 1988.

The role of research within the Division is to inform the policy development process within the U.S. Department of Health and Human Services by producing information on the organization, financing and delivery of services to chronically impaired populations. Recent work has centered on the needs of the impaired elderly and persons with mental retardation and other developmental disabilities.

ORGANIZATION

The booklet is divided into six subject areas:

- I. Financing Issues and the Economic Impact of Long-Term Care;
- II. Population Characteristics and Service Use;
- III. The Long-Term Care Service Delivery System;
- IV. Quality Issues;
- V. Disability Issues; and
- VI. Long-Term Care and Disability Data Needs.

Each subject is subdivided into: (A) Overview; (B) Completed Projects; (C) Ongoing or Planned Projects; and, (D) Other Related Reports.

Project descriptions include the title of the study, principal investigator, an abstract of the subject matter and findings, a list of reports, the project completion date and a division contact person. To obtain a copy of or information about the final report for completed studies, the reader should contact one of the following according to the code after each report:

[FCL] Brenda L. Veazey
Office of Family, Community and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201

[NTIS] National Technical Information Service
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5285 Port Royal Road
Springfield, Virginia 22161

I. FINANCING ISSUES AND THE ECONOMIC IMPACT OF LONG-TERM CARE

A. Overview

The bulk of the Division's research over the past several years has addressed long-term care financing issues affecting the elderly.

A number of related projects have been undertaken to estimate the likely impact of various reforms to the long-term care financing system. Early in 1992, **Lewin/ICF** completed work on a three year project to further develop the **Brookings/ICF Long-Term Care Financing Model** and make it accessible to researchers (**Long-Term Care Microsimulation Model**). Two major products resulted from this study--a final report describing the model and the simulations which have been performed, and the documentation for the public use version of this model. Readers should note that ASPE has made use of the model since 1985. A number of reports were generated using earlier versions of the model which has since been updated. These earlier simulations, reported on in Volume I of the research booklet, are now obsolete.

Two related studies of demand and financing have also recently been completed: a study of premiums for prototype private long-term care insurance policies (**Premium Pricing of Prototype Private Long-Term Care Insurance Policies**); and a study looking at the future demand for long-term care using simpler and more traditional modeling methods than the **Brookings/ICF** model (**The Future of Long-Term Care: Projections and Challenges**).

The affordability of long-term care and the economic burden on individuals who use long-term care services have also been examined. In particular, Medicaid spenddown has received attention. A number of recent studies have been completed using a unique longitudinal data base (**Estimates of Medicaid Asset Spend-down in Connecticut**). A paper has also been prepared synthesizing the major national and state studies on spenddown and analyzing their differences (**Synthesis of Medicaid Spend-down Studies**).

We have also begun to explore some of the interactions between acute and long-term care. A recent study on catastrophic acute and long-term care costs estimates the proportion of income spent by the elderly on payments for acute and long-term care services (**The Burden of Catastrophic Acute and Long-Term Care Costs**).

Finally, in cooperation with **SysteMetrics**, the Division is producing a number of monographs this year which analyze the long-term care financing and delivery system, and examine the characteristics and costs of proposals for reforming that system (**Long-Term Care Financing Policy Review**).

B. Completed Projects

TITLE: *ESTIMATES OF MEDICAID ASSET SPENDDOWN IN CONNECTICUT*

PRINCIPAL INVESTIGATOR: Not Applicable

SYNOPSIS: Several studies have made use of the unique opportunity offered by the Connecticut Nursing Home Patient Registry, a longitudinal data base which covers all persons admitted during the years 1978-1987. This data set attempts to get at lifetime use, which is particularly important to Medicaid spend-down since over half of the persons admitted to nursing homes have multiple stays. The likelihood of spending down during a stay is much higher if a person has had a previous stay. Three different methodologies have been applied to the data to estimate the extent of Medicaid asset spend-down.

Two studies by Bice emphasize the application of survival techniques to admission cohorts. In Nursing Home Stays and Spend-Down in the State of Connecticut: 1978-1983 mean lengths of stay are estimated for three groups of patients: private pay, Medicaid at admission, and Medicaid spend-down. Specific subgroups are examined using data on age and gender. The author concludes that nearly one person out of every four who enter nursing homes as private pay will eventually receive some assistance from the Medicaid program. In Nursing Home Stays and Spend-Down: State of Connecticut 1983-1984 Admission Cohort the contributions of the Medicare and Medicaid programs are examined, including the amounts of income (from Social Security and pensions) paid by Medicaid recipients toward their nursing home bills. The study finds that those who spend-down account for nearly 45% of the total number of persons receiving assistance from Medicaid, and consume nearly a third of Medicaid nursing home expenditures.

Gruenberg and his colleagues analyze data on a current resident cohort in An Analysis of the Impact of Spenddown on Medicaid Expenditures. This study estimates how many residents began their stays as private pay, but eventually spent down to Medicaid eligibility. It also estimates how many residents were Medicaid eligible prior to admission or became eligible at admission. Using data on the amount of income that nursing home residents on Medicaid applied to their bills, the author estimated the amounts of Medicaid funds provided for the care of various types of nursing residents. Those who spent down received nearly 38% of Medicaid expenditures.

Another study, by Liu and Manton, Nursing Home Length of Stay and Spend-down: Connecticut, 1977-1985, uses life table procedures to estimate length of stay distributions from nursing home patients in Connecticut. Three groups of patients were examined: private pay, Medicaid at admission, and Medicaid spend-down. According to the study, over 14% of all nursing home admissions (21% of non-Medicaid admissions) spent down to Medicaid eligibility. In addition, the authors found that Medicaid helped pay for 55% of the total nursing home days provided by Connecticut facilities.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: February 1992

REPORTS AVAILABLE: Nursing Home Stays and Spend-Down in the State of Connecticut: 1978-1983, Thomas W. Bice, September 20, 1990 [FCL]
Nursing Home Stays and Spend-Down: State of Connecticut 1983-84 Admission Cohort, Thomas W. Bice, June 1991 [FCL]
An Analysis of the Impact of Spenddown on Medicaid Expenditures, Leonard Gruenberg, Hillel Alpert, and Brian Burwell, January 1992 [FCL]
Nursing Home Length of Stay and Spend-down: Connecticut, 1977-1985, Korbin Liu and Kenneth Manton, August 1990 [FCL]

TITLE: FINANCING STUDIES USING NATIONAL NURSING HOME DATA

PRINCIPAL INVESTIGATOR: Korbin Liu, The Urban Institute, Washington, DC

SYNOPSIS: Two studies related to Medicaid spend-down were conducted using the 1985 National Nursing Home Survey (NNHS) and other data. In The Effects of Multiple Admissions on Nursing Home Use: Implications for "Front-end" Policies, the data were used to examine the phenomenon of multiple nursing home admissions. This was done to determine the number of individuals who would be fully covered if "front-end" financing options were enacted. Analysis of nursing home stays indicates that 51% of admissions would be fully covered by a three-month benefit, but adjusting for multiple admissions reduces this figure to 39% of cases. In Medicaid Spenddown in Nursing Homes and the Community, the NNHS data were used to examine the number of nursing home residents who entered a nursing home as a private pay and converted to Medicaid at some point during their stay. The author found that approximately 10% of nursing home stays involved spenddown to Medicaid eligibility.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: February 1992

REPORTS AVAILABLE: Medicaid Spenddown in Nursing Homes and the Community, Korbin Liu, Pamela Doty, and Kenneth Manton, 1990 [FCL] [NTIS]
Effects of Multiple Admissions on Nursing Home Use: Implications for "Front-end" Policies, Korbin Liu and Maria Perozek, September 1990 [FCL]

TITLE: LONG-TERM CARE MICROSIMULATION MODEL

PRINCIPAL INVESTIGATOR: David Kennell, Lewin/ICF, Inc., Washington, DC

SYNOPSIS: ASPE is using the Brookings/ICF Long-Term Care Financing Model to simulate the utilization and costs of nursing home and home care by impaired elderly persons for the period 1986-2020. The model has been updated to include the results of the 1984 National Long-Term Care Survey and the 1985 National Nursing Home Survey.

The long-term care model begins with a nationally-representative sample of the adult population generated from the pension and retirement income (PRISM) model developed by ICF, Inc. These data include age, sex, marital status, labor force participation, income, assets, and other characteristics. The model then simulates changes in the population each year, including changes in each individual's economic status, disability status, utilization of long-term care, and methods of paying for care.

Two reports developed from this project describe the model and the simulations which have been performed with it. Model Assumptions provides pertinent details about the variables, data, and equations on which the model is based. Desionina and Usina Model Simulations presents a base case projection which assumes that current public programs and private financing remain unchanged. In addition, the report contains simulations of various measures to promote the growth of private long-term care insurance and to expand/create public programs.

Given the long time period covered by these simulations, the results are sensitive to the choice of assumptions about the economy and individual behavior. For example, the ability of the elderly to pay for long-term care out of their own financial resources depends, in part, on how rapidly the cost of long-term care increases in future years.

The Brookings/ICF Long-Term Care Financing Model is available to interested researchers. However, access to a mainframe computer and significant amounts of computer time are required. The computer tape containing the code of the model and associated input data can be purchased through NTIS. Two

volumes of documentation have been prepared for those who have a serious interest in learning how to use the model. The User's Guide to Specifying Simulations discusses the parameters of the model and provides examples of how these parameters can be changed to simulate alternative scenarios of the utilization and financing of nursing home and home care by elderly persons for the period 1986-2020. The Programmer's/Operator's Manual provides additional information on the structure of the computer program.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: February 1992

REPORTS AVAILABLE: Brookings/ICF Lona Term Care Financia Model: Model Assumptions, David L. Kennell, Lisa Maria B. Alecxih, Joshua M. Wiener, and Raymond J. Hanley, February 1992 [FCL]

Brookings/ICF Lona Term Care Financia Model: Desianina and Usina Model Simulations, Lisa Maria B. Alecxih and David L. Kennell, February 1992 [FCL]

Brookings/ICF Lona Term Care Financia Model: User's Guide to Specifying Simulations, Lisa Maria B. Alecxih and Peter Robertshaw, February 1992 [FCL]

Brookings/ICF Lona Term Care Financia Model: Programmer's/Operator's Manual, Peter Robershaw and Lisa Maria B. Alecxih, February 1992 [FCL]

TITLE: **SYNTHESIS OF MEDICAID SPENDDOWN STUDIES**

PRINCIPAL INVESTIGATOR: Brian Burwell, SysteMetrics, Lexington, MA

SYNOPSIS: Medicaid spenddown is a topic of considerable interest in long-term care policy because it is an indication of the catastrophic impact of long-term care expenses on the economic status of disabled elderly persons. This paper provides an overview of recent research on Medicaid spend-down in nursing homes. It addresses major conceptual, methodological, and measurement issues, and provides a synthesis of recent findings. Implications for long-term care policy and directions for future research are discussed. The report concludes that between one in four and one in five persons enter nursing homes as private pays and spend-down to Medicaid eligibility. The report also concludes that more longitudinal data bases are needed to determine whether the research results apply to other states. More information is also needed on the process of spend-down, e.g., do the elderly liquidate their home equity to pay for care, do they transfer assets to children?

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: February 1992

REPORT AVAILABLE: A Synthesis and Critiaue of Studies on Medicaid Asset Spenddown, E. Kathleen Adams, Mark R. Meiners, and Brian O. Burwell, January 1992 [FCL]

TITLE: **THE BURDEN OF CATASTROPHIC ACUTE AND LONG-TERM CARE COSTS**

PRINCIPAL INVESTIGATOR: Korbin Liu, The Urban Institute, Washington, DC

SYNOPSIS: This study used the National Long-Term Care Survey and other data sources to estimate the extent to which acute and long-term care service use cause disabled elderly persons to incur catastrophic costs. The impact of these costs is measured by proportion of income. Overall, about 30% of the disabled elderly living in the community spent more than 20% of their income on acute and long-term care. However, there is considerable variation across income groups. In the lowest income group, 42% spent more than 20% of their income on care, while only 11% in the highest income group spent that much.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172
COMPLETION DATE: February 1992
REPORT AVAILABLE: Catastrophic Acute and Long-Term Care Costs: Risks Faced by Disabled Elderly Persons, Korbin Liu, Maria Perozek, and Kenneth Manton, June 1991 [FCL]

TITLE: THE FUTURE OF LONG-TERM CARE: PROJECTIONS AND CHALLENGES

PRINCIPAL INVESTIGATOR: Bob Applebaum, Miami University of Ohio, Scripps Gerontology Center, Oxford, OH

SYNOPSIS: This study used data from the Decennial Census of Population and Housing, the National Long-Term Care Survey, and the National Nursing Home Survey to develop projections of the need for long-term care among the elderly in the years 2000, 2020, and 2040. The study prepared three different sets of projections, using a dynamic projections model with assumptions about future mortality and morbidity varying between the different sets.

The authors' constant model shows 4.9 million severely disabled in 2020, and another 4.8 million moderately disabled, of a total elderly population of 52.1 million. These numbers are generally consistent with estimates generated by the Brookings/ICF Long-Term Care Financing Model. A longer life/lower disability estimate for 2020 results in somewhat lower estimates, with 4.8 million severely disabled and 4.6 million moderately disabled of a total elderly population of 57.5 million. Assuming longer life with higher disability instead gives much higher disability numbers--7.0 million severely disabled and 6.6 million moderately disabled, of the same 57.5 million elderly population. The numbers in 2040 are generally consistent with this picture, but much higher, due to the aging of the baby boom population.

For other papers from this study, contact Robert Applebaum, Scripps Gerontology Center, Oxford, Ohio 45056; (513)529-2914.

CONTACT PERSON: Paul Gayer, ASPE, (202)245-6172
COMPLETION DATE: February 1991
REPORT AVAILABLE: Estimating the Prevalence of Long-Term Disability for an Aging Society, Suzanne R. Kunkel and Robert A. Applebaum, April 1991 [FCL]

TITLE: PREMIUM PRICING OF PROTOTYPE PRIMATE LONG-TERM CARE INSURANCE POLICIES

PRINCIPAL INVESTIGATOR: Joshua Wiener, The Brookings Institution, Washington, DC

SYNOPSIS: This project generated estimates of benefits, costs and premiums for prototype long-term care insurance policies to provide Federal, State, and local governments and private insurance companies with an independent estimate of the potential for long-term care insurance coverage. The conclusions were that premiums were especially sensitive to: age at purchase; whether or not the policy was fully indexed for inflation; whether or not the policy offered has a nonforfeiture benefit equal to the full asset share; and length of coverage of care.

CONTACT PERSON: Paul Gayer, ASPE, (202)245-6172
COMPLETION DATE: December 1990
REPORT AVAILABLE: Premium Pricing of Prototype Private Long-Term Care Insurance Policies, Joshua M. Wiener, Katherine M. Harris, and Raymond J. Hartley, December 1990 [FCL]

TITLE: *THE USE, COST, AND ECONOMIC BURDEN OF NURSING HOME CARE IN 1985*
PRINCIPAL INVESTIGATOR: Thomas Rice, University of North Carolina, Chapel Hill, NC

SYNOPSIS: This study used the 1985 National Nursing Home Survey to examine the use and cost of nursing home care among the elderly population of the United States. The following questions were addressed: How many persons aged 65 and older used nursing homes in a given year? How long do they stay and what are their annual charges? How often, and, to what extent, do residents "spenddown" to Medicaid? How much of the annual charges were paid by various payers; in particular, what are annual out-of-pocket costs?

The study found that approximately 2.1 million persons aged 65 and older (7.5% of the United States elderly population) spent some time in a nursing home during 1985. Over 70% were women and nearly two-thirds were single, widowed or divorced women. Mean charges per nursing home user in 1985 were \$9,600 and median charges were \$7,700. About 53% of 1985 nursing home costs were paid privately, out-of-pocket, 35% by Medicaid, 8% by Medicare, and 4% by other sources. About 22% of nursing home residents who entered nursing homes as private pay patients became eligible for Medicaid during their stay.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172
COMPLETION DATE: January 1989
REPORT AVAILABLE: The Use, Cost, and Economic Burden of Nursing Home Care in 1985, Thomas Rice, January 1989 [FCL] [NTIS]

C. Ongoing and Planned Projects

TITLE: *MODELING THE SUPPLY OF HOME CARE WORKERS*
PRINCIPAL INVESTIGATOR: To be determined

SYNOPSIS: This project is intended to gain a better understanding of the market for home care workers including the potential competition for workers of this type from other industries. The study will build on projections and models which already exist, such as the Bureau of Labor Statistics Occupational Outlook Projections as well as studies which have been done for specific States. It may be conducted intramurally.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172
COMPLETION DATE: To be determined
REPORT AVAILABLE: none at the time of this printing

TITLE: THE LONG-TERM CARE MICROSIMULATION MODEL: UPDATE AND REVISIONS

PRINCIPAL INVESTIGATOR: To be determined

SYNOPSIS: This project will update and support the Long-Term Care Microsimulation Model over the next three years, permitting later data to be added to the model (e.g., 1989 and 1993 National Long-Term Care Surveys) and the project period to be extended beyond 2020 to encompass the period of maximum impact of the baby boom on long-term care demand. It will also provide analytical support for modeling of long-term care options in Administration planning and legislative proposals.

CONTACT PERSON: Paul Gayer, ASPE, (202)245-6172

COMPLETION DATE: To be determined

REPORT AVAILABLE: none at the time of this printing

TITLE: LONG-TERM CARE IN COMPARATIVE INTERNATIONAL PERSPECTIVE

PRINCIPAL INVESTIGATOR: Pamela Doty, ASPE, Washington, DC

SYNOPSIS: This ongoing research involves tracking developments in long-term care financing and delivery in other countries. The current focus is on lessons to be learned from the recent implementation of Israel's new long-term care insurance law. Past research has focused on comparative cross-national institutionalization rates, the balance of medical to non-medical long-term care institutional use, effectiveness of funding home and community-based care to prevent or postpone institutionalization, relative reliance on public versus private financing and differences in public financing mechanisms. A paper on comparative financing methods was presented at the Brookings Institution conference in May 1988 and a general overview of long-term care in international perspective, highlighting comparative institutionalization rates, was published in the Health Care Financing Review 1988 Supplement.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172

COMPLETION DATE: Ongoing

REPORTS AVAILABLE: Lona-Term Care in International Perspective, Pamela Doty, 1988 [FCL] [NTIS]
Dispelling Some Myths: A Comparison of Lona-Term Care Financing in the U.S. and Other Nations, Pamela Doty, 1990 [FCL]
U.S. Lona-Term Care Financing in Comparative International Perspective: Old Myths, New Ideas, Pamela Doty, April 1990 [FCL]

TITLE: LONG-TERM CARE FINANCING POLICY REVIEW

PRINCIPAL INVESTIGATOR: Brian Burwell, SysteMetrics, Lexington, MA

SYNOPSIS: In cooperation with SysteMetrics, the Division is producing five monographs which review what we have learned about key long-term care problems and issues. A summary report, Analysis of Lona-Term Care Financing Choices: If You Don't Know Where You're Going, You May End Up Somewhere Else, assesses the strengths and weaknesses of the current system, and critically analyzes various reforms which have been proposed. Data on the numbers of disabled elderly and their use of nursing and home care services are presented in The Disabled Elderly and Their Use of Lona-Term Care. The current status of the public long-term care system is discussed in Federal and State Roles in the Financing of Lona-Term Care Services. Recent developments in private long-term care insurance are presented in The New Kid on the Block: The Emergence of Private Lona-Term Care Insurance. Finally, the affordability of long-term care services and of private long-term care insurance policies are analyzed in The

Economic Impact of Long-Term Care on Individuals. This report also contains projections of future expenditures for long-term care services.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172
COMPLETION DATE: 1992
REPORT AVAILABLE: none at the time of this printing

TITLE: **SOURCES OF PAYMENT AND CHARACTERISTICS OF FLORIDA NURSING HOME RESIDENTS**

PRINCIPAL INVESTIGATORS: Kathleen Adams, SysteMetrics, Lexington, MA
Brian Burwell, SysteMetrics, Lexington, MA

SYNOPSIS: This project will create a longitudinal data base on all nursing home residents in Florida. The data base will be used in future analyses of Medicaid spend-down, changes in sources of payment over time, and characteristics of nursing home residents. Data from the Florida Nursing Home Reporting System will be merged with Medicare and Medicaid claims.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172
COMPLETION DATE: 1992
REPORT AVAILABLE: none at the time of this printing

D. Other Related Reports

1. Kennell, David: Private Financing of Long-Term Care: Current Methods and Resources, January 1985 [NTIS]
2. Kennell, David L., Lisa Alexih, Joshua M. Wiener, and Raymond Hanley: Financing of Long-Term Care, September 30, 1988 [FCL]
3. Technical Work Group on Private Financing of Long-Term Care: Report to the Secretary on Private Financing of Long-Term Care for the Elderly, November 1988 [NTIS]
4. Wiener, Joshua M., Raymond J. Hanley, Denise A. Spence, and Sheila Murray: Estimating the Demand for and Impact of Private Sector Financing Options for Long-Term Care, February 9, 1987 [FCL] [NTIS]

II. POPULATION CHARACTERISTICS AND SERVICE USE

A. Overview

Projects in this area reflect a continuing emphasis on basic and descriptive research to understand the demographic and functional characteristics of the elderly long-term care population and predictors of long-term care service use. Recent work has addressed issues associated with using functional impairment measures as eligibility criteria for home care and the measurement of unmet need among the impaired elderly population in the community.

Finally, a monograph, The Disabled Elderly and Their Long-Term Care Use, is being prepared as part of the Long-Term **Care Financing Policy Review**. (See Section I).

B. Completed Projects

TITLE: HOME AND COMMUNITY-BASED CARE IN THE USA

PRINCIPAL INVESTIGATOR: Robert F. Clark, ASPE, Washington, DC

SYNOPSIS: This paper describes the use of long-term care services by the frail elderly, particularly home and community-based care. It describes the functionally disabled elderly population (aged 65+) and provides an overview of the United States' long-term care system. The paper discusses: (a) Medicare home health care; (b) Medicaid home health care; (c) Medicaid personal care services; and (d) Medicaid home and community-based care under Section 2176 of OBRA 1981, Section 1915(d) of Title XIX as authorized by OBRA 1987, and Section 4711 of OBRA 1990. It addresses other sources of support for home and community-based care such as the Older Americans Act, the Social Services Block Grant, Supplemental Security Income, and various types of support, housing arrangements. Finally, a list of surveys, administrative data systems and other sources of data on home and community-based care are briefly described.

This paper was prepared as background information for the members of an international long-term care research team. The team is focusing on international comparisons of nursing home care, with emphasis on appropriate outcome measures, data sources and comparability of data elements. The project is sponsored under the aegis of the International Collaborative Effort on Aging, organized by the National Center for Health Statistics.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443

COMPLETION DATE: December 1991

REPORT AVAILABLE: Home and Community-Based Care in the USA, Robert F. Clark, October 1991
[FCL]

TITLE: *PHYSICAL AND COGNITIVE IMPAIRMENT: DO THEY REQUIRE DIFFERENT KINDS OF HELP?*

PRINCIPAL INVESTIGATOR: Robert F. Clark, ASPE, Washington, DC

SYNOPSIS: Physical impairments are commonly believed to require relatively more active hands-on assistance with the Activities of Daily Living (ADL) while cognitive impairments use relatively more supervisory or standby assistance. Using data from the 1984 National Long-Term Care Survey, this paper examines whether the type of assistance (active, standby, assistive device, and combinations thereof) varies by cognitive status. It differs from prior studies by focusing on how assistance patterns might vary for specific ADLs. Generally, the cognitively impaired use standby help twice as frequently as the cognitively intact regardless of ADL. They also use active help and assistive devices more frequently but the disparity with the cognitively intact is not so great. Additionally, there are exceptions for particular ADLs (e.g., the rate of use of assistive devices in bathing is higher among the cognitively intact). There appears to be a relationship between cognitive status and type of ADL help received, but it is subtle and varies by ADL.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443

COMPLETION DATE: August 1991

REPORT AVAILABLE: Physical and Cognitive Impairment: Do They Require Different Kinds of Help?
Robert F. Clark, 1991 [FCL]

TITLE: *UNMET NEED AMONG THE ELDERLY WITH ADL DISABILITIES*

PRINCIPAL INVESTIGATOR: Mary E. Jackson, SysMetric, Lexington, MA

SYNOPSIS: Numerous attempts have been made over the past few years to estimate the number of elderly persons who are disabled. Fewer estimates have been generated to gauge the extent to which such persons go without the assistance they need. In this study estimates of unmet need were generated using the community resident (noninstitutional) sample of the 1984 National Long-Term Care Survey. Estimates of the number of frail elderly with unmet needs depend crucially on how "disability" and "unmet need" are defined and measured. Using a variety of definitions, the study found that the number of frail elderly with unmet needs can range from approximately 199,000 to 1.8 million in 1990. This translates to between 5.3% and 42.0% of the disabled elderly population.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: February 1991

REPORT AVAILABLE: Prevalence and Correlates of Unmet Need Among the Elderly with ADL Disabilities, Mary E. Jackson, February 1991 [FCL]

TITLE: *MEASURING THE ACTIVITIES OF DAILY LIVING: COMPARISONS ACROSS NATIONAL SURVEYS*

PRINCIPAL INVESTIGATOR: Interagency Forum on Aging-Related Statistics, Washington, DC

SYNOPSIS: The Activities of Daily Living (ADL) are the basic activities of everyday life, such as eating, bathing, dressing, transferring, and toileting. Reported estimates of the size of the elderly population with ADL disabilities differ substantially across national surveys. Differences in which ADL items are being measured and what constitutes a disability account for much of the variation. When essentially equivalent ADLs are compared across 11 national surveys, estimates for the community-based population with ADL limitations range from 5.0% to 8.1%. Policy analysts need to think carefully about their definitions of ADL disability and specify in greater details the bases of their results.

This study resulted from a project of the Interagency Forum on Aging-Related Statistics. The Forum's Committee on Estimates of the Activities of Daily Living in National Surveys was chaired by Robert F. Clark (ASPE) and Joan Van Nostrand (National Center for Health Statistics). The report to the Forum from which this article was adapted was prepared by Joshua Wiener and Raymond Hanley of the Brookings Institution.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443
COMPLETION DATE: December 1990
REPORT AVAILABLE: Measuring the Activities of Daily Living: Comparisons Across National Surveys.
Joshua M. Wiener, Raymond J. Hanley, Robert F. Clark, and Joan Van Nostrand, 1990 [FCL]

TITLE: PREVALENCE ESTIMATES OF THE FUNCTIONALLY IMPAIRED ELDERLY

PRINCIPAL INVESTIGATOR: Mary Jackson, SysMetric, Lexington, MA

SYNOPSIS: Numerous proposals have been advanced for establishing a uniform Federal benefit for home care services for the disabled elderly. This paper operationalizes eligibility criteria invoked in these proposals, and offers estimates for the number who would be eligible under alternative functional and cognitive criteria. Differing cut-off points (i.e., number and type of activities of daily living), in conjunction with varied definitions of disability (need for active, standby, or mechanical assistance in the performance of activities of daily living) are employed in order to demonstrate their effect on the number and types of persons eligible under a uniform Federal home care benefit. When functional criteria only are used, estimates range from 472,000 to over three million, or 1.6%-12.5% of the communitydwelling population, aged 65 or older. By adding cognitive impairment to eligibility criteria the number eligible increases to between approximately one million and 4.2 million elders (3.5%-14.0%). Programmatic issues related to using functional and cognitive criteria for eligibility determination are discussed.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443
COMPLETION DATE: June 1990
REPORT AVAILABLE: Publicly-Financed Home Care for the Disabled Elderly: Who Would be Eligible?
Mary E. Jackson and Brian O. Burwell, December 1990 [FCL]

TITLE: RISK OF INSTITUTIONALIZATION: 1977-1985

PRINCIPAL INVESTIGATOR: Ernest Schoenfeld, University of North Carolina, Chapel Hill, NC

SYNOPSIS: This study compares the determinants of institutionalization for two time periods, 1977 and 1985, and identifies factors, such as supply, that are associated with any perceived differences between the periods. Data sources include the 1977 and 1985 National Nursing Home Surveys, the 1984 Health Interview Survey/Supplement on Aging, and the 1977 Health Interview Survey. The study attempts to establish a better understanding of the determinants of institutionalization and enhance capability of home and community-based care providers to control case mix. A product of the project is a kit that practitioners of home and community-based care can use to assess the probable risk of institutionalization of their clients and applicants.

CONTACT PERSON: Floyd Brown, ASPE, (202)245-6443
COMPLETION DATE: January 1990
REPORT AVAILABLE: Risk of Institutionalization: 1977-1985, William G. Weissert, Jennifer M. Elston, and Gary G. Koch, July 24, 1990 [FCL]

TITLE: CHARACTERISTICS OF THE ELDERLY LONG-TERM CARE POPULATION AND ITS SERVICE USE
PRINCIPAL INVESTIGATOR: Kenneth Manton, Duke University, Durham, NC

SYNOPSIS: With a grant from ASPE, the Center for Demographic Studies at Duke University has produced a series of studies covering the characteristics of the elderly long-term care population and its use of services. The studies rely on data from the National Long-Term Care Surveys (1982 and 1984), the National Long-Term Care Channeling Demonstration, and other sources. These studies have used sophisticated analytical techniques like Grade of Membership and life tables. The papers cover a variety of issues, including functional transitions at advanced ages and trends in community care and institutional service use. To obtain the full set of articles and published papers, contact Dr. Kenneth Manton, Center for Demographic Studies, Duke University, 2117 Campus Drive, Durham, North Carolina 27706, (919)684-6126.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: 1990

REPORTS AVAILABLE: Risks of Enterina Nursina Homes for Lona and Short Stavs, Korbin Liu, Carol DeVita, Kenneth G. Manton, and Terri Coughlin, 1988 [FCL]
The Effect of Nursina Home Use on Medicaid Eliaibiitv, Korbin Liu and Kenneth G. Manton, 1989 [FCL] [NTIS]
Recent Chanaes in Service Use Patterns of Disabled Medicare Beneficiaries, Kenneth G. Manton and Korbin Liu, 1990 [FCL]
Morbidity, Disability, and Lona-Term Care: Implication for Public and Private Policies [Contact Kenneth Manton]

TITLE: LONG-TERM CARE SERVICE USE: LONGITUDINAL AND PREDICTIVE MODELS

PRINCIPAL INVESTIGATOR: John Morris, Hebrew Rehabilitation Center for the Aged, Boston, MA

SYNOPSIS: Under an ASPE grant, the investigators examined a sample of 2,898 elderly persons living in the community in Massachusetts. They were age 62 or older when interviewed in 1982 and 66 or older when re-interviewed in 1986. Residential settings included private homes, apartments in facilities for the elderly, and private apartments. For sample members surviving over the four year period, institutional placements were relatively rare. Informal support was available to most elders. Formal care was a factor in the lives of large numbers of the elderly living in the community; for those in apartments, this was related to a statewide program of case managed home care services. The authors recommend replication of the study in other states. This would yield descriptive information of value for more effective organization of services for the frail elderly.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: February 1989

REPORT AVAILABLE: Lona-Term Care Service Use: Lonaitudinal and Predictive Models, John N. Morris, Claire E. Gutkin, Hirsch S. Ruchlin, and Sylvia Sherwood, March 1989 [FCL] [NTIS]

TITLE: SMALL AREA SYNTHETIC ESTIMATION OF DEPENDENCY

PRINCIPAL INVESTIGATOR: William Weissert, University of North Carolina, Chapel Hill, NC

SYNOPSIS: While a substantial portion of long-term care planning occurs at the State and local level, most prevalence rate estimates on functional dependency are only reliable nationally. The study pro-

duced models that estimate the prevalence of functional dependency among the noninstitutionalized elderly for small areas (States and counties) for each of three income groups: household income less than \$3,000; \$3,000-40,000; and greater than \$40,000. Specific estimates of functional dependency for each State and selected counties were also made. Software showing how to do these analyses were developed and disseminated to State and local officials. The data sets employed include the 1980 Census, the 1977, 1979 and 1980 National Health Interview Surveys, and the 1977 National Nursing Home Survey.

CONTACT PERSON: Floyd Brown, ASPE, (202)245-6443
COMPLETION DATE: January 1989
REPORT AVAILABLE: Small Area Estimation of Deoendency Final Report, William G. Weissert, Jennifer M. Elston, Gary G. Koch, Jane D. Darter, and William D. Kalsbeek, February 13, 1989 [FCL]

C. Ongoing or Planned Projects

TITLE: INTERNATIONAL COMPARISONS IN LONG-TERM CARE: SERVICE USE

PRINCIPAL INVESTIGATOR: Robert F. Clark, ASPE, Washington, DC

SYNOPSIS: This paper examines the residential settings and long-term care service use of the frail elderly in five countries: Australia, Canada, Netherlands, Norway and the United States. Problems of making cross-national comparisons are noted, particularly the lack of a standard definition of a "nursing home" and wide variation in data collection systems. With 1985 as a comparison year, in all countries, the percentage of elderly living independently at home is quite high, approaching 90% in some cases. Nursing home admission rates are lowest in the Netherlands (3.0%). In Norway and the Netherlands, nursing homes are developing into more rehabilitative and respite-oriented facilities. Home and community care systems have expanded in recent years in all countries, especially in Canada. Australia has shifted the balance between nursing homes and hostels. Concern over the appropriate balance between public and private financing is greatest in the United States.

This paper will be merged with papers prepared by other members of an international long-term care research team. The result will be an article for the International Journal of Health Sciences on the measurement of nursing home outcomes. The project is part of a number of international data and measurement initiatives sponsored by the International Collaborative Effort on Aging, organized by the National Center for Health Statistics.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443
COMPLETION DATE: 1993
REPORT AVAILABLE: none at the time of this printing

TITLE: LIFESTYLE PATTERNS AND NURSING HOME USE

PRINCIPAL INVESTIGATOR: Robert F. Clark, ASPE, Washington, DC

SYNOPSIS: This paper will examine the relationship between specific lifestyle behaviors--namely, smoking, alcohol use, exercise, and weight control--and nursing home use among the elderly. The data come from the 1988 National Mortality Followback Survey. Preliminary findings are that, as expected, weight

control and exercise can help reduce the risk of nursing home use. Less expected are indications that persons with a history of smoking and alcohol use also are associated with lower nursing home use, even while controlling for age. Since it is unlikely that such persons are less disabled, it may mean that they are accounted for disproportionately in other long-term care settings, such as board and care homes.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443
COMPLETION DATE: June 1992
REPORT AVAILABLE: none at the time of this printing

TITLE: THE USE OF HEALTH-RELATED AND SUPPORT SERVICES BY THE FUNCTIONALLY DISABLED ELDERLY LIVING IN THE COMMUNITY

PRINCIPAL INVESTIGATOR: Robert F. Clark, ASPE, Washington, DC

SYNOPSIS: This paper will address the use of various health-related and supportive services by the frail elderly living in the community. The data come from the 1984 National Long-Term Care Survey. The paper will present a series of cross-tabulations showing the use of various services by persons aged 65-74, 75-84, and 85+. The services will include: (a) adult day care/senior center; (b) prior nursing home use; (c) nursing home wait list; (d) hospital stay; (e) therapy: physical, occupational, speech; (f) mental health services; (g) selected medical specialty: dentist, foot doctor, optometrist, chiropractor; (h) emergency room or hospital clinic; (i) availability of a regular source of medical care; and (j) home health aide or nurse's aide services.

A draft of this paper was prepared as background information for the members of an international long-term care research team. The team is focusing on international comparisons of nursing home care, with emphasis on appropriate outcome measures, data sources and comparability of data elements. The project is sponsored under the aegis of the International Collaborative Effort on Aging, organized by the National Center for Health Statistics.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443
COMPLETION DATE: June 1992
REPORT AVAILABLE: none at the time of this printing

D. Other Related Reports

1. Adler, Michele, Suzanne Kitchen and Albert Irion: Databook on the Elderly: A Statistical Portrait, June 1987 [FCL] [NTIS]
2. Jackson, Mary E., and Brian O. Burwell: Use of Functional Criteria in Allocating Long-Term Care Benefits: What are the Policy Implications?, November 1989 [FCL]
3. Liu, Korbin, and Kenneth G. Manton: Effects of Medicare's Hospital Prospective Payment System (PPS) on Disabled Medicare Beneficiaries, February 1988 [FCL] [NTIS]
4. Wiener, Joshua M., and Raymond J. Hanley: Measuring the Activities of Daily Living Among the Elderly: A Guide to National Surveys, October 1989 [FCL] [NTIS]

III. THE LONG-TERM CARE SERVICE DELIVERY SYSTEM

A. Overview

Research in this area addresses the characteristics and outcomes associated with both the formal and informal systems of delivering long-term care services and how the two systems interact.

The major research project of the Division in this area was the National Long-Term Care Channeling Demonstration co-sponsored with the Health Care Financing Administration and the Administration on Aging. This multi-year, ten State randomized experiment was designed to test the cost-effectiveness of comprehensive case management and home care. The reports from this demonstration contain a great deal of information on home and community-based services, and the data base should be a rich source for further research for years to come. The final report on Channeling and the public use tapes were published in 1986 (**National Long-Term Care Channeling Demonstration**). A recent project which uses the Channeling data is **Reducing Nursing Home Utilization Costs Through Community-Based Long-Term Care: An Optimization Analysis Using Data from the National Channeling Demonstration**.

Other Division studies recently completed or underway include a **Survey of Medicaid Personal Care Programs**, and a number of studies on informal caregiving. Also underway and not yet completed is a study of **Supportive Housing for the Frail Elderly**. The Division is also carrying a new initiative on informal caregiving which will culminate in a conference in the fall of 1992.

B. Completed Projects

TITLE: ASSISTIVE TECHNOLOGY FOR THE FRAIL ELDERLY

PRINCIPAL INVESTIGATOR: Robert Elliott, University of Pennsylvania, University Park, PA

SYNOPSIS: This paper, prepared by an ASPE student intern, provides an overview of assistive technology for the frail elderly. According to the Office of Technology Assessment, in 1985 there were over 18,000 devices available to aid the functionally impaired elderly. The number has grown since then. The devices range in sophistication from a modified eating utensil to computerized voice simulators. The paper discusses barriers to the acceptance of assistive technology, such as inadequate training of users and inappropriate match of equipment of needs. The author concludes that properly used, assistive technology can help improve the quality of life for the frail elderly and enable many people to remain functionally independent. Assistive devices can also alleviate some of the burden of informal caregivers. From a research perspective, the overall costs, benefits and financing of assistive technology need to be better understood.

CONTACT PERSON: Robert F. Clark, ASPE, (202)245-6443

COMPLETION DATE: February 1992

REPORT AVAILABLE: Assistive Technology for the Frail Elderly: An Introduction and Overview, Robert Elliott, December 2, 1991 [FCL]

TITLE: SYNTHESIS OF LITERATURE ON NURSING HOME ACCESS

PRINCIPAL INVESTIGATOR: Korbin Liu, The Urban Institute, Washington, DC

SYNOPSIS: This study reviews the evidence on access to nursing home beds and concludes that several elderly who seek admission to nursing homes in some geographic areas are unable to obtain access. In particular, those with heavy care needs may experience discharge delays in hospitals, and Medicaid enrollees tend to have greater access problems than private pay patients. The limited supply of nursing home beds appears to be the primary reason for access problems.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: February 1992

REPORT AVAILABLE: Is There a Nursing Home Access Problem? A Review of the Empirical Evidence,
Lisa C. Dubay, Timothy D. McBride, and John Holahan, August 1990 [FCL]

TITLE: SURVEY OF MEDICAID PERSONAL CARE PROGRAMS

PRINCIPAL INVESTIGATOR: Simi Litvak, World Institute on Disability, Oakland, CA

SYNOPSIS: Although the Medicaid home and community-based waiver program has been extensively studied, spending for home and community-based care is actually higher under the Medicaid personal care option. Drawing on 1985 and 1989 data from a 50 state survey of home attendant programs for the elderly and younger physically disabled populations, the study provides a statistical profile of all Medicaid personal care programs as compared to programs supported by other Federal and state funding sources. The comparative statistical data is supplemented by in-depth case studies of six Medicaid personal care programs to highlight the unique features of particular state approaches to philosophy and organization.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172

COMPLETION DATE: April 1991

REPORTS AVAILABLE: Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit (Volume I), Simi Litvak and Jae Kennedy, December **1991** [FCL]
Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit: Appendices A through E (Volume II), Simi Litvak and Jae Kennedy, December **1991** [FCL]
Case Studies of Six State Personal Assistance Service Programs Funded by the Medicaid Personal Care Option (Volume III), Jae Kennedy and Simi Litvak, December 1991 [FCL]

TITLE: FACTORS ASSOCIATED WITH A BREAKDOWN IN CAREGIVING AMONG INFORMAL CAREGIVERS TO THE FUNCTIONALLY AND COGNITIVELY IMPAIRED ELDERLY POPULATION

PRINCIPAL INVESTIGATOR: Judith Kasper, Johns Hopkins University, Baltimore, MD

SYNOPSIS: This study investigated the reasons that principal informal caregivers of the activity of daily living (ADL) dependent elderly decided to end caregiving. Data were from the 1982 and 1984 National Long-Term Care Surveys and the 1982 Informal Caregiver Survey. Two definitions of "ending caregiving" were used in the analyses: the first included all reasons why a particular individual chose to end caregiving other than the care recipients' death; the second definition looked at the decision to end informal caregiving in the community by placing the disabled elderly person in a nursing home. In the first definition, institutionalization was the outcome **in only about half the decisions**; in the other half of the cases, either the individual had recovered and no longer needed care or some other family member was now

providing care. Factors associated with the decisions to end caregiving under both definitions included a non-spouse caregiver and assisting the elderly care recipient **with** three or more ADL impairments. Factors found to be specifically associated with the decision to seek institutional placement were the care recipient's cognitive impairment and the caregiver's expressed view that caregiving was "emotionally difficult." Being unable to leave the care recipient alone and experiencing more stress than satisfaction from the caregiving role were also related to decisions to end caregiving under the broader definition.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172
COMPLETION DATE: February 1990
REPORT AVAILABLE: Factors Associated with Endina Careaivina Among Informal Careaivers to the Functionally and Coanitively Impaired Elderly Population, Judith D. Kasper, February 1990 [FCL]

TITLE: PROSPECTIVE OUTCOMES OF INFORMAL AND FORMAL HOME CARE: TIME TO INSTITUTIONALIZATION OR MORTALITY

PRINCIPAL INVESTIGATOR: Burton Dunlop, Project HOPE, Chevy Chase, MD

SYNOPSIS: The purpose of this project was to identify combinations of formal and informal caregiving that are better than others in preventing or delaying mortality or nursing home placement. A competing risks model was employed to predict time elapsed to death or institutionalization. Primary data sources included the Longitudinal Study of Aging, National Death Index and Medicare Part A records.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172
COMPLETION DATE: December 1989
REPORT AVAILABLE: Prospective Outcomes of Informal and Formal Home Care: Mortality and Institutionalization, Burton D. Dunlop and James A. Wells, December 19, 1990 [FCL]

TITLE: REDUCING NURSING HOME UTILIZATION COSTS THROUGH COMMUNITY-BASED LONG-TERM CARE: AN OPTIMALIZATION ANALYSIS USING DATA FROM THE NATIONAL CHANNELING DEMONSTRATION

PRINCIPAL INVESTIGATOR: Vernon L. Greene, Syracuse University, Syracuse, NY

SYNOPSIS: A consistent finding of community-based long-term care demonstrations, including Channeling, is that these programs do not lead to net reductions in long-term care expenditures. Even though reducing nursing home costs was a goal of these demonstrations, none involved systematic managerial and resource allocation strategies specifically designed to reach this goal. Rather, resource allocation decisions were left largely to the professional judgment of case managers. This study addressed whether long-term care resources can in fact be allocated strategically among clients to reduce nursing home use and costs. It used the techniques of econometrics and mathematical optimization to address this question, using data from the Channeling demonstration. Essentially, the study found that higher skilled rather than lower skilled care in the community was a more cost-effective way to delay or prevent institutionalization.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443
COMPLETION DATE: December 1989
REPORT AVAILABLE: Reducing Nursing Home Use Throuah Community-Based Lona-Term Care: An Odimization Analysis, Vernon L. Greene, Mary M. Lovely, Mark Miller and Jan I. Ondrich, October 1989 [FCL]

TITLE: *CAREGIVER BURDEN AND INSTITUTIONALIZATION, HOSPITAL USE AND STABILITY OF CARE*

PRINCIPAL INVESTIGATOR: Baila Miller, University of Illinois, Chicago, IL

SYNOPSIS: This study assessed a variety of longitudinal models to examine the effect of different types of caregiver burden on outcomes important to policymakers: nursing home admissions, hospital use, and stability of the family and formal care networks. Analyses were carried out on the 1982 National Long-Term Care Survey (NLTCs), a nationally representative sample of the functionally disabled elderly living in the community, and the 1984 NLTCs Longitudinal Followup, along with the 1982-1983 Informal Caregiver Survey, a representative sample of informal caregivers of the moderate to severely disabled elderly in the NLTCs (those with one or more ADL impairment). Among the findings: informal caregiver networks were found to be highly stable over time; formal caregiver networks fluctuated more, apparently responding more to time-specific needs. Caregivers who reported higher levels of "personal burden" (a dimension that included a number of elements such as lack of free time, having to provide care when the caregiver was sick, the caregiver experiencing worsening health, having to provide constant attention, etc.) were more likely over time to use or increase use of formal services. Caregivers who reported higher levels of "interpersonal burden" (a dimension that measured stress-producing characteristics of the care recipient such as senility, forgetfulness, yelling, and embarrassing behavior) were more likely over time to seek institutional placement for the elderly disabled care recipient.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172

COMPLETION DATE: November 1989

REPORT AVAILABLE: Caregiver Burden and Institutionalization, Hospital Use, and Stability of Care,
Baila Miller and Stephanie McFall, November 1989 [FCL]

C. Ongoing or Planned Projects

TITLE: *INFORMAL CARE OF THE DISABLED ELDERLY- A RESEARCH AND POLICY INITIATIVE*

PRINCIPAL INVESTIGATORS: Brian Burwell, Systemetrics, Lexington, MA

Mary E. Jackson, Systemetrics, Lexington, MA

SYNOPSIS: This project encompasses: (1) analysis of family caregiving patterns in the 1989 National Long-Term Care (NLTCs) and companion Informal Caregivers Survey (ICS) as well as analysis of trends in family caregiving based on comparison with previous (1982 and 1984) NLTCs/ICS data; and (2) organization of a national conference on informal caregiving to assess the state-of-the-art in policy research with respect to such issues as work/caregiving conflicts, stress and satisfaction among family caregivers, integration of formal and informal services, and the role of volunteers and community organizations.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172

COMPLETION DATE: December 1992

REPORT AVAILABLE: none at the time of this printing

TITLE: POLICY SEMINAR ON SUPPORTIVE HOUSING FOR THE FRAIL ELDERLY

PRINCIPAL INVESTIGATOR: Barbara B. Manard, Lewin/ICF, Inc., Washington, DC

SYNOPSIS: Under a task order contract to Lewin/ICF, ASPE is conducting a research project on Supportive Housing for the Frail Elderly. The purpose of the project is to: (a) examine the range of housing and service options available to the frail elderly; (b) identify critical public policy issues in the financing, delivery, and appropriateness of supportive housing alternatives; and (c) assist ASPE in developing a policy-relevant research agenda in supportive housing.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: September 1992

REPORT AVAILABLE: none at the time of this printing

TITLE: POLICY IMPLICATIONS OF THE PAST DECADE'S RESEARCH ON HOME AND COMMUNITY-BASED CARE

PRINCIPAL INVESTIGATOR: Pamela Doty, ASPE, Washington, DC

SYNOPSIS: This project is synthesizing the major findings of ten years of DHHS sponsored policy research on home and community-based long-term care, encompassing major national surveys of long-term care needs and service use as well as research and demonstration projects testing the effectiveness of proposed financing and organizational reforms.

CONTACT PERSON: Pamela Doty, ASPE, (202)245-6172

COMPLETION DATE: June 1992

REPORT AVAILABLE: none at the time of this printing

D. Other Related Reports

1. Applebaum, Robert A., and Margaret Harrigan: Channelina Effects on the Quality of Clients' Lives, April 1986 [NTIS]
2. Applebaum, Robert A., Randall S. Brown, and Peter Kemper: An Analysis of Site-Specific Results, May 1986 [NTIS]
3. Applebaum, Robert A., Margaret N. Harrigan, and Peter Kemper: Tables Comparing Channelina to Other Community Care Demonstrations, May 1986 [NTIS]
4. Baxter, Raymond J., Robert Applebaum, James J. Callahan, Jr., Jon B. Christianson, and Stephen L. Day: The Planning and Implementation of Channelina: Early Experiences of the National Long-Term Care Demonstration, April 15, 1983 [NTIS]
5. Brown, Randall S., and Margaret Harrigan: The Comparability of Treatment and Control Groups at Randomization, October 27, 1983 [NTIS]
6. Brown, Randall S., and Peter A. Mossel: Examination of the Equivalence of Treatment and Control Groups and the Comparability of Baseline Data, October 1984 [NTIS]
7. Brown, Randall S., Peter A. Mossel, Jennifer Schore, Nancy Holden, and Judy Roberts: Final Report on the Effects of Sample Attrition on Estimates of Channelina's Impacts, January 13, 1986 [NTIS]
8. Brown, Randall, and Barbara Phillips: The Effects of Case Management and Community Services on the Impaired Elderly, February 1986 [NTIS]

9. Brown, Randall S.: Methodological Issues in the Evaluation of the National Long-Term Care Demonstration, July 1986 [NTIS]
10. Carcagno, George J., Robert Applebaum, Jon Christianson, Barbara Phillips, Craig Thornton, and Joanna Will: The Planning and Operational Experiences of the Channelina Projects, (2 volumes), July 18, 1986 [NTIS]
11. Christianson, Jon B., and Susan A. Stephens: Informal Care to the Impaired Elderly: Report to the National Long-Term Care Demonstration Survey of Informal Caregivers, June 6, 1984 [NTIS]
12. Christianson, Jon B.: Channelina Effects on Informal Care, May 1986 [NTIS]
13. Cohen, E., and L. Sterthous: Community Services and Long-Term Care: Issues of Neutrality and Liability, 1982 [NTIS]
14. Corson, Walter, Thomas Grannemann, Nancy Holden, and Craig Thornton: Channelina Effects on Formal Community Based Services and Housing, May 1986 [NTIS]
15. Grana, John M., and Sandra M. Yamashiro: An Evaluation of the Veterans Administration Homebound and Aid and Attendance Allowance Program, April 15, 1987 [NTIS]
16. Grannemann, Marilyn: The Channelina Financial Control System, 1985 [NTIS]
17. Grannemann, Thomas W., Randall S. Brown, and Shari Miller Dunstan: Differential Impacts Among Subgroups of Channelina Enrollees Six Months After Randomization, July 1984 [NTIS]
18. Grannemann, Thomas W., and Jean Baldwin Grossman: Differential Impacts Among Subgroups of Channelina Enrollees, May 1986 [NTIS]
19. Johnson, M., and L. Sterthous: A Guide to Memorandum of Understanding Negotiation and Development, 1982 [NTIS]
20. Kemper, Peter, Robert Applebaum, Raymond J. Baxter, James J. Callahan, Jr., George J. Carcagno, Jon B. Christianson, Stephen L. Day, Thomas W. Grannemann, Jean Baldwin-Grossman, and Judith Wooldridge: Research Design of the National Long-Term Care Demonstration, November 1982 [NTIS]
21. Kemper, Peter, Robert Applebaum, Randall S. Brown, George J. Carcagno, Jon B. Christianson, Thomas W. Grannemann, Margaret Harrigan, Nancy Holden, Barbara Phillips, Jennifer Schore, Craig Thornton, and Judith Wooldridge: Channelina Effects for an Early Sample at 6-Month Followup, May 1985 [NTIS]
22. Kemper, Peter, Randall S. Brown, George J. Carcagno, Robert A. Applebaum, Jon B. Christianson, Walter Corson, Shari Miller Dunstan, Thomas Grannemann, Margaret Harrigan, Nancy Holden, Barbara Phillips, Jennifer Schore, Craig Thornton, Judith Wooldridge, and Felicity Skidmore: The Evaluation of the National Long-Term Care Demonstration: Final Report, May 1986 [NTIS]
23. Kemper, Peter, Robert Applebaum, and Margaret Harrigan: A Systematic Comparison of Community Care Demonstrations, June 1987 [NTIS]
24. Kemper, Peter, Randall S. Brown, George J. Carcagno, Robert A. Applebaum, Jon B. Christianson, Walter Corson, Shari Miller Dunstan, Thomas Grannemann, Margaret Harrigan, Nancy Holden, Barbara R. Phillips, Jennifer Schore, Craig Thornton, Judith Wooldridge, and Felicity Skidmore: Health Services Research Special Issue: The Evaluation of the National Long-Term Care Demonstration, April 1988 [FCL]
25. Mathematica Policy Research: National Long-Term Care Channelina Demonstration: 18 Public Use Data Files and Documentation [NTIS]
26. Mathematica Policy Research: National Long-Term Care Channelina Demonstration: Various Data Collection Instruments (included in various reports and data tape documentation)
27. Mossel, Peter A., and Randall S. Brown: The Effects of Sample Attrition on Estimates of Channelina's Impacts for an Early Sample, July 1984 [NTIS]
28. National Governor's Association: State Long-Term Care Reform: Development of Community Care Systems in Six States, April 1988 [NTIS]
29. Newman, Sandra, Michelle Rice and Raymond Struyk: Overwhelming Odds: Caregiving and the Risk of Institutionalization, June 1987 [FCL]
30. Office of Family, Community and Long-Term Care Policy: National Long-Term Care Channeling Demonstration Summary of Demonstration and Reports, August 1989 [FCL]

31. Phillips, Barbara, Raymond J. Baxter, and Susan A. Stephens: Issues in Developing the Client Assessment Instrument for the National Long-Term Care Channeling Demonstration, January 1981 [NTIS]
32. Phillips, Barbara R., Susan A. Stephens, and Joanna J. Cerf: Survey Data Collection Design and Procedures: Overview of Data Collection in the National Long-Term Care Demonstration, March 7, 1986 [NTIS]
33. Solen, Elizabeth, Marilyn Grannemann, Elsie Carter, Helen Wells-Hunter, Patricia Decker, Suzanne Bulvanoski, Carol Coleman, Maryellen Kluxen, and Tambria Johnson: Assessment and Care Planning for the Frail Elderly: A Problem Specific Approach, 1986 [NTIS]
34. Sterthous, Linda M.: Informal Services and Supports, 1985 [NTIS]
35. Temple University: Applicant Screen Set, 1982 [NTIS]
36. Temple University: Clinical Baseline Assessment Instrument Set, 1983 [NTIS]
37. Temple University: Assessment Training for Case Managers: A Trainer's Guide, 1985 [NTIS]
38. Temple University: Case Management Forms Set, 1985 [NTIS]
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40. Temple University: Screening Training for Screeners: A Trainer's Guide, 1985 [NTIS]
41. Temple University: The Channeling Case Management Manual, 1986 [NTIS]
42. Thornton, Craig, and Shari Miller Dunstan: Analysis of the Benefits and Costs of Channeling, May 1986 [NTIS]
43. Thornton, Craig, Joanna Will, and Mark Davies: Analysis of Channeling Project Costs, May 1986 [NTIS]
44. Wooldridge, Judith, and Jennifer Schore: Channeling Effects on Hospital, Nursing Home and Other Medical Services, May 1986 [NTIS]

IV. QUALITY OF CARE

A. Overview

Research in this section addresses long-term care quality concerns including the quality of public home and community-based services, quality concerns surrounding residential arrangements for persons with disabilities and consumer protection issues arising from the emergence of private sector financing arrangements. Recently work was completed on a study of the issues related to **Consumer Protection and Private Long-Term Care Insurance**. The Division is also engaged in a major study of the quality of care in board and care homes with an emphasis on the role of state regulation in promoting quality. Past work included a study of the quality of the post acute care system **Pilot Study of the Adequacy of Post-Hospital Community Care for the Elderly**.

B. Completed Projects

TITLE: CONSUMER PROTECTION AND PRIVATE LONG-TERM CARE INSURANCE

PRINCIPAL INVESTIGATOR: David Kennell, Lewin/ICF, Inc., Washington, DC

SYNOPSIS: This paper reviews the current status of consumer protection issues associated with private long-term care insurance. It examines possible roles that the Federal government might play in this area. The views of a panel of experts drawn from government, industry, academia, and consumer organizations are reported. The panel concluded that the Federal government could make an important contribution by educating consumers about long term care insurance and related issues. Clarifying the tax status of these products, collecting better data on the risk of long term care, and expanding the capabilities of state insurance departments would also help. The panel did not reach consensus on whether certain specific features should be required on all policies, e.g., inflation protection and nonforfeiture benefits. These issues are currently under review by the National Association of Insurance Commissioners Long Term Care Task Force.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: February 1992

REPORT AVAILABLE: The Federal Role in Consumer Protection and Regulation of Long-Term Care Insurance, Lisa Alexih and Dave Kennell, June 1991 [FCL]

TITLE: AFFECTING THE QUALITY OF COMMUNITY SERVICES FOR PEOPLE WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

PRINCIPAL INVESTIGATOR: Tecla Jaskulski, Jaskulski and Associates, Highland, MD

SYNOPSIS: The purpose of this study was to collect background information and identify issues related to the Federal role in assuring and promoting quality home and community-based services for people with developmental disabilities. Underlying the project was a clear distinction between: (a) minimum compliance with regulations; and (b) proactive efforts to enhance programs. The goal was to identify a way to promote the latter without compromising the former. The researcher reviewed recent literature on quality

assurance, conducted site visits to four states with innovative quality systems (Connecticut, Michigan, Oregon, and Pennsylvania), and held discussions with Federal and state agency staff, advocates, Congressional staff, providers and researchers. The researcher identified significant gaps in the knowledge base, most significantly, the question of how to translate values and mission statements into quality system design and service delivery.

CONTACT PERSON: Ruth Katz, ASPE, (202)245-6443
COMPLETION DATE: February 1991
REPORT AVAILABLE: No report; Executive Summary available [FCL]

TITLE: *PILOT STUDY OF THE ADEQUACY OF POST-HOSPITAL COMMUNITY CARE FOR THE ELDERLY*
PRINCIPAL INVESTIGATOR: Barbara Phillips, Mathematica Policy Research, Inc., Princeton, NJ

SYNOPSIS: One prominent response of hospitals to the necessity of controlling costs under Medicare's Prospective Payment System (PPS) has been a reduction in hospital lengths of stay. Patients appear to be sicker when they are discharged now than was the case prior to PPS. Sicker patients probably require more health and personal care services upon discharge.

The current evidence on the adequacy of post-hospital community care is largely impressionistic. A systematic assessment is required to develop objective evidence on the extent of problems and whether they lead to adverse health outcomes for patients. The methodology available up to now had not been adequate to support a systematic assessment of national scope. The primary limitation of this methodology is that it has required physician review of individual cases, which is difficult to implement in a national study and has often been found to be unreliable.

This study, sponsored jointly with the Health Care Financing Administration's Office of Research and Demonstrations, developed and tested a new methodology intended to overcome these limitations and to permit a systematic, national assessment of the adequacy of post-hospital care in the community for elderly patients and whether inadequate care leads to adverse health outcomes. The key to this methodology is a series of "guidelines" which specify standards for the amount of care that is minimally adequate to prevent adverse health outcomes for elderly patients with a wide variety of conditions commonly requiring post-hospital care in the community.

The methodology was implemented in a pilot study in nine hospitals in two states. The conclusion of the pilot is that the methodology is generally valid, feasible, and effective although some refinements are required. The guidelines (taken as a group) provide a reasonable definition of minimally adequate care.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443
COMPLETION DATE: October 1939
REPORTS AVAILABLE: A Pilot Study of the Adequacy of Post-Hospital Community Care for the Elderly: Final Report, Barbara R. Phillips, September 13, 1939 [FCL] [NTIS]
Pilot Study of the Appropriateness of Post-Hospital Care Received by Medicare Beneficiaries: Clinical Case-by-Case Review, Lawrence Markson, Marilyn Pajk, Keith Champney, and Knight Steel, October 3, 1939 [FCL] [NTIS]

C. Ongoing or Planned Projects

TITLE: ANALYSIS AND COMPARISON OF STATE BOARD AND CARE REGULATIONS AND THEIR EFFECT OF THE QUALITY OF CARE IN BOARD AND CARE HOMES

PRINCIPAL INVESTIGATOR: Catherine Hawes, Research Triangle Institute, Research Triangle Park, NC

SYNOPSIS: The primary objectives of this project are to determine the quality of care in board and care homes, how it varies across states and programs and between licensed and unlicensed homes, and to examine the effect of regulation on quality. To accomplish these objectives the project will: (1) identify and examine the factors associated with differences in quality, with particular emphasis on the effect of regulation; (2) describe generally the regulatory systems in 50 states and describe in detail the system in the ten study states; (3) describe the key characteristics of the board and care industry in the study sample--the homes, the owners/operators, the staff, the residents, and the care and services that residents receive; and (4) compare the performance of licensed and unlicensed board and care homes.

CONTACT PERSON: Floyd Brown, ASPE (202)245-6443

COMPLETION DATE: November 1993

REPORT AVAILABLE: none at the time of this printing

D. Other Related Reports

1. Macro Systems, Inc.: Review of State Quality Assurance Programs for Home Care, April 1989 [FCL]
2. Office of the Assistant Secretary for Planning and Evaluation: National Conference on Home Care Quality: Issues and Accountability--Conference Package, June 1, 1988 [FCL] [NTIS]
3. Office of the Assistant Secretary for Planning and Evaluation: National Conference on Home Care Quality: Issues and Accountability--Volume I Proceedings, 1989 [FCL] [NTIS]

V. DISABILITY ISSUES

A. Overview

Most of the Division's research in disability focuses on people with mental retardation or other developmental disabilities (MR/DD) who are likely to need long-term services and supports. The Division has sponsored studies to define the population, examine their characteristics, service needs and where they live, and identify how services are financed.

In late 1988, ASPE released the final report of the Departmental Working Group on MR/DD Financing (**Report to the Secretary from the Working Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled Persons**). This report examined Federal policy barriers to community-based services and outlined alternative reform strategies. More recently the Division completed a study of children with high medical care costs to determine their characteristics and Medicaid experience (**Study of Disabled or High Cost Children**).

The Division has initiated several new disability related projects over the past few years including: a study of health care financing issues affecting children and working age adults with disabilities, using the National Health Interview Survey; and a study of community supported living services targeted at persons with MR/DD.

B. Completed Projects

TITLE: COMMUNITY PROGRAM SIZE AND QUALITY

PRINCIPAL INVESTIGATOR: James Conroy, Temple University, Philadelphia, PA

SYNOPSIS: The project examined the relationship between community residential size and quality of care for persons with developmental disabilities. Differences in cost and among small facilities (less than ten residents) are of special interest. Results are based on data from the National Consumer Survey and from detailed analysis of two States--Connecticut and Pennsylvania. Overall, information from the National Consumer Survey indicate that generally people are more satisfied and better integrated in group homes with less than ten residents than in larger places. Data from the two States show that while there are no real differences in family/consumer satisfaction between group homes of size 5 and size 7 or 8, there appears to be more satisfaction in group homes below size 5. Cost data are mixed. Smaller group homes in Pennsylvania appear to cost slightly more, but no relationship between cost and size in Connecticut can be ascertained.

CONTACT PERSON: Michde Adler, ASPE, (202)245-6172

COMPLETION DATE: March 1992

REPORT AVAILABLE: Size and Quality in Residential Programs for People with Developmental Disabilities, James W. Conroy, February 1992 [FCL]

TITLE: STUDY OF MEDICAID FINANCING FOR DISABLED OR HIGH COST CHILDREN

PRINCIPAL INVESTIGATOR: Marilyn Rymer Ellwood, **Systemetrics**, Lexington, MA

SYNOPSIS: The Congress, DHHS, and other Federal agencies have expressed considerable interest in the adequacy of current programs and policies affecting severely disabled children, particularly those who are technology dependent and whose health and medical care place catastrophic financing and caregiving burdens on their families. This project used the Medicaid tape-to-tape and other data to estimate the numbers of children experiencing catastrophic health care expenses, the level of expenditures and sources of payment and their service utilization patterns.

All children who qualify for Medicaid through the Supplemental Security Income (SSI) program are studied in SSI-Related Disabled Children and Medicaid. This report analyzed the 1984 Medicaid claims of all children with SSI-related Medicaid coverage in California, Georgia, and Michigan in order to determine the enrollment, utilization, and expenditure patterns of these children. The study estimated the proportion of Medicaid expenditures attributable to SSI-related disabled children.

Variations in the Medicaid Safety Net for Children and Youth with High Medical Costs: A Comparison of Four States analyzed the Medicaid experience of children and young adults with total annual Medicaid claims of \$25,000 or more in California, Georgia, Michigan, and Tennessee in order to better understand service utilization patterns and how they vary by age and other characteristics. An important part of the study involved analysis of the Medicaid eligibility pathways.

Longitudinal Analysis of High Cost Medicaid Children in California follows a cohort of children for several years during the 1980s. This report analyzed the Medicaid experience of children in California who had at least \$25,000 in claims in 1988. The study analyzed Medicaid claims over the period 1980-1986 in order to determine whether these children remain high cost over a number of years, and whether their eligibility changes over time.

The relationship between Medicaid and other payers in California is examined using data on all pediatric hospitalizations in Who is Paying the Bills? Very High Cost Pediatric Hospitalizations in California, 1987. This report analyzed data on all pediatric hospitalizations costing \$25,000 or more in California to determine the relationship between source of payment and various characteristics, including age and diagnosis.

The results contained in each of the papers are summarized in the Summary and Policy Implications.

CONTACT PERSON: John Drabek, ASPE, (202)245-6172

COMPLETION DATE: December 1990

REPORTS AVAILABLE: Summary and Policy Implications: Analyses of Medicaid Financing for Disabled and High Cost Children, Marilyn Rymer Ellwood and Leighton Ku, December 1990 [FCL]
SSI-Related Disabled Children and Medicaid, Marilyn Rymer Ellwood, June 1990 [FCL]
Variations in the Medicaid Safety Net for Children and Youth with High Medical Costs: A Comparison of Four States, Brian Burwell, Elicia Herz, and John Drabek, November 1990 [FCL]
Who is Paying the Bills? Very High Cost Pediatric Hospitalizations in California, 1987, Leighton Ku, August 1990 [FCL]
Longitudinal Analysis of High Cost Medicaid Children in California, Marilyn Rymer Ellwood and Elicia Herz, October 1990 [FCL]

C. Ongoing or Planned Projects

TITLE: *THE COSTS AND BENEFITS OF OFFERING SUPPORTED EMPLOYMENT AND PREVOCATIONAL TRAINING FOR PERSONS WITH DEVELOPMENTAL DISABILITIES UNDER MEDICAID*

PRINCIPAL INVESTIGATOR: To be determined

SYNOPSIS: This project will identify the ways that Medicaid can be used to finance supported employment and prevocational services for beneficiaries with mental retardation and related conditions. The potential cost and impact of these services will be analyzed. As part of this research, information would be collected on the feasibility and appropriateness of offering supported employment and prevocational services to all waiver participants, community supported living arrangement participants and ICF/MR residents. The researcher will identify barriers and develop policy options to expand supported employment services. One shorter term goal of this study will be to determine if the waiver authority should be expanded to cover supported employment for all MR/DD participants, whether this would involve increases in waiver expenditures and, if so, to try to estimate the costs.

CONTACT PERSON: Ruth Katz, ASPE, (202)245-6443

COMPLETION DATE: To be determined

REPORT AVAILABLE: none at the time of this printing

TITLE: *STUDY OF THE MEDICALLY UNINSURED, MENTAL ILLNESS AND MENTAL RETARDATION, AND FAMILIES WITH DISABILITIES*

PRINCIPAL INVESTIGATOR: Mitchell LaPlante, University of California, San Francisco, CA

SYNOPSIS: The purpose of this project is to provide three special studies of health and long-term care financing issues affecting nonelderly persons with disabilities. The three studies will be derived from nearly a decade of data from the National Health Interview Survey (NHIS). These studies are:

- The Medically Uninsurable Study will examine the number and characteristics of persons unable to obtain health insurance, because of a disability or chronic medical condition. Comparisons will also be made to disabled persons with health insurance, nondisabled persons without health insurance, and the general population. This report will synthesize health insurance trends during the 1980s for persons with disabilities.
- The Mental Illness and Mental Retardation Study will provide a profile of children, working-age adults, and older people with mental illness or mental retardation who reside in community settings. The profile would focus on the size and characteristics of the two groups and examine closely the degree to which mental illness or mental retardation is linked to limitation of activity. This report would use the 1989 Mental Health Supplement, along with data from previous years of the NHIS.
- The Disability and the Family Study will examine the prevalence of disability in families, as other sources suggest that when one member of the family is disabled, there is a high probability that there are other disabled persons in the family as well. Various years of the NHIS will be used.

CONTACT PERSON: Michele Adler, ASPE, (202)245-6172

COMPLETION DATE: March 1993

REPORT AVAILABLE: none at the time of this printing

TITLE: *DISABILITY IN AMERICA-1990*

PRINCIPAL INVESTIGATORS: John McNeil, Bureau of the Census, Washington, DC
Michele Adler, ASPE, Washington, DC

SYNOPSIS: This project will produce a monograph describing the extent of disability throughout the nation, in all **50** states and the District of Columbia, and in every country. The monograph will contain state-of-the-art knowledge on the size, characteristics, and geographic distribution of Americans with disabilities. The information will be especially useful to state and local officials and planners and for international comparisons. No other such information has ever been available before at local levels. In addition, the monograph will be particularly timely in relation to the ADA. The information would be chiefly derived from data collected in the **1990** Census, which will be available during 1992, but other sources will be used as well.

CONTACT PERSON: Michele Adler, ASPE, (202)245-6172
COMPLETION DATE: 1993
REPORT AVAILABLE: none at the time of this printing

TITLE: *COMMUNITY SUPPORTED LMNG SERVICES*

PRINCIPAL INVESTIGATOR: Brian Burwell, **SysteMetrics**, Lexington, MA

SYNOPSIS: Community supported living programs are a significant departure from traditional, continuum-based, developmental models of residential services for people with developmental disabilities. Several state mental retardation service systems, as well as national policy leaders have embraced supported living approaches, recognizing them as a vehicle to translate into reality the lofty goals of independence, integration, and productivity. The Department has encouraged the growth of these models in its home and community-based waiver program and in the new "community supported living arrangements" (CSLA) Medicaid state plan option.

With this project, the Division is taking a closer look at how supported living programs work, identifying strengths and weaknesses of the approach, and beginning to quantify cost and program effectiveness. The project will provide descriptions of five established community supported living programs for people with developmental disabilities. The project will identify the elements of these programs that contribute to their success. In addition, national data on the strengths and weaknesses, cost-effectiveness and extent of the use of this model is being collected and analyzed. The project staff will work with experts to develop a short and long range research agenda on community supported living services. The final product will be a policy paper which describes the programs that were visited, and outlines the policy issues in this new service modality. The paper will also include an evaluation plan for **CSLA**.

CONTACT PERSON: Ruth Katz, ASPE, (202)245-6443
COMPLETION DATE: August 1992
REPORT AVAILABLE: none at the time of this printing

D. Other Related Reports

1. Adler, Michele: Health and Disability Status of AFDC Families, 1998 [FCL]
2. Adler, Michele: The Disabled: Their Health Care and Health Insurance, August **1990** [FCL]

3. Adler, Michele: The Future of SIPP for Analyzing Disability and Health, April 1991 [FCL]
4. Burwell, Brian O.: Federal Programs for Persons with Disabilities (Task II), January 1990 [FCL] [NTIS]
5. Conroy, James W., and Valerie J. Bradley: The Pennhurst Longitudinal Study: A Report of Five Years of Research and Analysis, March 1, 1985 [NTIS]
6. Doyle, Pat: Population Profile of Disability (Task I), October 1989 [FCL] [NTIS]
7. Doyle, Pat, Esther Miller and Jim Sears: Program Participation Patterns Among Persons with Disabilities (Task III), May 10, 1990 [FCL] [NTIS]
8. Hill, Bradley K., K. Charlie Lakin, Angela R. Novak, and Carolyn C. White: Foster Care for Children and Adults with Handicaps: Child Welfare and Adult Social Services, October 1987 [FCL] [NTIS]
9. Jaskulski, Tecla, and Rebecca Weader: An Analysis of Federal and State Policies Affecting Services to Mentally Retarded and Other Developmentally Disabled Persons: State Perspectives, July 1987 [FCL] [NTIS]
10. Kottler, Martin, George Wright, Tecla Jaskulski, and Ilene Kreisberg: Synthesis of Cost Studies on the Long-Term Care of Health-Impaired Elderly and Other Disabled Persons (2 volumes), June 1985 [NTIS]
11. Martini, Alberto: A Labor Force Profile of Persons with Disabilities (Task IV), March 19, 1990 [FCL] [NTIS]
12. Report from the Working Group on Improving Public Policies and Programs Affecting Persons with Mental Retardation and Other Developmental Disabilities, December 1988 [FCL] [NTIS]

VI. LONG-TERM CARE AND DISABILITY DATA NEEDS

A. Overview

The Division has a long-standing commitment to improving basic data on disability and long-term care. In recent years, it has sponsored the National Long-Term Care Survey including the National Survey of Caregivers in 1982, cooperated with the National Long-Term Care Survey of 1984, and co-sponsored the National Long-Term Care Survey of 1989. Public use files have been made available from the National Long-Term Care Channeling Demonstration. In addition, a Conference on DHHS Long-Term Care Data Bases was held in 1987 to enhance their accessibility to researchers and private insurers. Current efforts include support of the National Mortality Followback Survey of 1988, and a design study for a national survey of people with developmental disabilities and a design study for board and care homes.

B. Completed Projects

TITLE: NATIONAL BOARD AND CARE SURVEY DESIGN

PRINCIPAL INVESTIGATOR: Mary Naifeh, Bureau of the Census, Washington, DC

SYNOPSIS: Board and care living arrangements for dependent populations (frail elderly, developmentally disabled and mentally ill) are an increasingly important part of the long-term care continuum. Under an interagency agreement with ASPE and the Office of the Assistant Secretary for Health, the Census Bureau examined the feasibility of using the 1990 Census as a sampling frame for a national survey of licensed and unlicensed board and care homes. A feasibility study was conducted in Missouri, which was the 1988 dress rehearsal site for the 1990 Census. Based on the results, two separate instruments were recommended for a national survey, one for housing units and one for group quarters (institutional and noninstitutional). Other recommendations included more refined screening procedures and additional questions to distinguish board and care homes from more professional and medically-oriented places. With these changes, the study concluded that the decennial census provides a feasible frame for identifying and obtaining data from a nationally representative sample of board and care homes.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: September 1991

REPORT AVAILABLE: Searchina for a Needle in a Havstack: Creative Use of the Decennial Census (Dress Rehearsal Data to Find Board and Care Places in Central Missouri), Mary Naifeh and William Downs, February 1992 [FCL]

TITLE: DATA BASE TECHNICAL ASSISTANCE/CHANNELING

PRINCIPAL INVESTIGATOR: Shari Dunstan, Mathematica Policy Research, Inc., Princeton, NJ

SYNOPSIS: This project provided on-going technical assistance to users of the Channeling data base and made enhancements to the public use tapes and documentation based on user critiques.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: August 1990

REPORT AVAILABLE: No final report for public distribution, but four new files (with documentation) were added to the public use data tapes at NTIS. Also SAS versions of selected files were made available through NTIS.

TITLE: INCLUSION OF BOARD AND CARE HOMES IN 1991 NATIONAL HEALTH PROVIDER INVENTORY

PRINCIPAL INVESTIGATOR: Jade Gong, Lewin/ICF, Inc., Washington, DC

SYNOPSIS: Under a task order contract, Lewin/ICF generated an unduplicated computerized listing of all potential licensed board and care homes nationally. As part of the National Center for Health Statistics' 1991 update of the National Health Provider Inventory, the Census Bureau will contact places on the listing to see if they are board and care homes, and, if so, their key characteristics.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: June 1990

REPORT AVAILABLE: Descriptions of and Supplemental Information on Board and Care Homes included in the Update of the National Health Provider Inventory, Lewin/ICF and James Bell Associates, August 8, 1990 [FCL] [NTIS]

TITLE: DESIGN STUDY FOR A NATIONAL SURVEY OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

PRINCIPAL INVESTIGATOR: Craig Thornton, Mathematica Policy Research, Inc., Princeton, NJ

SYNOPSIS: This study analyzed methods for collecting nationally representative data on people with mental retardation and other developmental disabilities living in the community. An operational definition of the proposed survey population was developed and functional measures identified. The project analyzed existing surveys which include information on the target population, recommended modules for enhancing the usefulness of existing surveys and developed a prototype data collection instrument and sampling frame for a new survey. A Technical Advisory Group comprised of Federal and State officials as well as outside consultants provided oversight.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: February 1990

REPORTS AVAILABLE: An Estimate of the Number of Persons with Developmental Disabilities Receiving Supplemental Security Income Benefits and Their Characteristics, Brian O. Burwell, December 1990 [FCL] [NTIS]
Characteristics of Persons with Developmental Disabilities: Evidence from the Survey of Income and Proaram Participation, Craig Thornton, January 1990 [FCL]
Desian for a National Survey of Persons with Developmental Disabilities, Craig Thornton, et al., February 1990 [FCL] [NTIS]

Design for a National Survey of Persons with Developmental Disabilities: Prototype Instrument. Susan A. Stephens, et al., February 1990 [FCL] [NTIS]
Persons with Mental Retardation and Related Conditions in Mental Retardation Facilities: Selected Findings from the 1987 National Medical Expenditure Survey. K. Charlie Lakin, et al., December 1989 [FCL]

TITLE: NATIONAL LONG-TERM CARE SURVEY

PRINCIPAL INVESTIGATOR: Kenneth Manton, Duke University, Durham, NC

SYNOPSIS: A grant from the National Institute on Aging (NIA) to Duke University supported the creation of a longitudinal data set comprised of three waves of the National Long-Term Care Survey (1982, 1984, and 1989) conducted by the Census Bureau and data extracted from Medicare Part A files (1980-1989). The focus is on changes in functional and health characteristics as well as long-term care service use among a nationally representative sample of elderly impaired persons.

The Division supplemented the NIA grant to permit additional data collection in three areas: (a) the effects of supply on the use of long-term care services, (b) the treatment of income and assets by persons with nursing home stays, and (c) patterns of informal caregiving. A public use tape is available.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443

COMPLETION DATE: 1990

REPORT AVAILABLE: The National Long-Term Care Surveys (1982, 1984, 1989), March 1992 [FCL]

TITLE: NATIONAL LONG-TERM CARE SURVEY USERS FORUM

PRINCIPAL INVESTIGATOR: Ase Sewell, Social and Scientific Systems, Washington, DC

SYNOPSIS: The National Long-Term Care Survey is a very rich yet complex data base involving three separate interview waves (1982, 1984, and 1989) and multiple components. The complexity of the data base had led to a number of issues related to utilization of the Survey for research purposes. As part of its objective to encourage the utilization of data bases, sponsored by DHHS, ASPE held a one-day forum for users of the National Long-Term Care Survey.

CONTACT PERSON: Floyd Brown, ASPE, (202)245-6443

COMPLETION DATE: February 1989

REPORT AVAILABLE: Report on Problems and Suggestions for Improving the NLTCs Files for 1982 and 1984, Social and Scientific Systems, Inc., May 17, 1989 [FCL] [NTIS]

TITLE: NATIONAL MORTALITY FOLLOWBACK SURVEY

PRINCIPAL INVESTIGATOR: Gloria Kapantais, National Center for Health Statistics, Rockville, MD

SYNOPSIS: The 1988 National Followback Survey is a nationally representative sample of 20,000 persons who died in 1988. The survey contains information about health and functional status of the decedent and the use of acute and long-term care services in the year prior to death. The survey was designed and managed by the National Center for Health Statistics; data collection was carried out by the Census Bureau. Nine agencies inside and outside the Department provided funding and technical sup-

port. ASPE provided funding and support to acquire data on impairments and use of long-term care services in the last year of life.

CONTACT PERSON: Robert Clark, ASPE, (202)245-6443
COMPLETION DATE: 1969
REPORT AVAILABLE: Data tape available from Principal Investigator.

C. Ongoing or Planned Projects

**TITLE: NATIONAL SURVEY OF THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED/
COORDINATED DISABILITY SURVEY**

PRINCIPAL INVESTIGATOR: Not applicable

SYNOPSIS: Persons with mental retardation or other developmental disabilities (MR/DD) are a population of particular policy interest to ASPE. The absence of nationally representative data on the size and characteristics of the MR/DD population has been a significant barrier to estimating the budgetary impact and program outcomes of alternative financing options. To obtain information about the MR/DD population and other disabled populations (disabled children, SSI recipients, SSDI recipients), the National Center for Health Statistics is planning to conduct in 1993 and 1994 a supplement to the National Health Interview Survey called the Coordinated Disability Survey. ASPE has provided impetus for the survey, provided initial funding (for the MR/DD portion) through interagency transfers and contributed to the survey design and development of questionnaires. At present, Phase One, which will screen for the disabled population and obtain preliminary data, is scheduled for implementation. Phase Two is detailed followup interviews with persons screened in as disabled to collect service use and expenditure data is under development.

CONTACT PERSONS: Michele Adler, ASPE, (202)245-61 72 (for overall CDS)
Robert Clark, ASPE, (202)245-6443 (for MR/DD survey)
COMPLETION DATE: 1995
REPORT AVAILABLE: none at the time of this printing

TITLE: REPORT OF THE DEPARTMENTAL COORDINATING GROUP ON DISABILITY DATA

PRINCIPAL INVESTIGATOR: Lawrence Haber, Lawrence Haber & Associates, Washington, DC

SYNOPSIS: The purpose of this project is to prepare the written report of the Departmental Coordinating Group on Disability Data. The Group was created by ASPE in 1969 in order to provide a policy framework for the many policy issues (i.e., employment, access to health care, and long-term care) that face the Department pertaining to the nonelderly disabled.

The report will contain: (1) descriptions of planned and on-going Federal disability data collection efforts; (2) key disability policy issues; (3) definitional and measurement problems; (4) the availability and adequacy of information on special populations, such as the mentally retarded/developmentally disabled, the mentally ill, and physically disabled adults; (5) gaps in disability data; and (6) specific recommendations for satisfying policy research needs on disability during the coming decade.

Information was compiled from presentations made by individual agencies at the Group's meetings and interviews with Departmental policymakers.

CONTACT PERSON: Michele Adler, ASPE, (202)245-6172

COMPLETION DATE: May 1992

REPORT AVAILABLE: none at the time of this printing

D. Other Related Reports

1. Office of Family, Community and Long-Term Care Policy: National Invitational Conference on Long-Term Care Data Bases: Summary of Conference Package, May 21, 1987 [NTIS]
2. Office of Family, Community and Long-Term Care Policy: ~~National Invitational Conference on Long-Term Care Data Bases: Summary of Conference Proceedings~~, 1988 [FCL] [NTIS]